

Tilburg University

Support needs of parents with intellectual disabilities

Koolen, J.; van Oorsouw, W. M. W. J.; Verharen, L.; Embregts, P. J. C. M.

Published in:
Journal of Intellectual Disability Research

DOI:
[10.1177/1744629519829965](https://doi.org/10.1177/1744629519829965)

Publication date:
2020

Document Version
Publisher's PDF, also known as Version of record

[Link to publication in Tilburg University Research Portal](#)

Citation for published version (APA):
Koolen, J., van Oorsouw, W. M. W. J., Verharen, L., & Embregts, P. J. C. M. (2020). Support needs of parents with intellectual disabilities: Systematic review on the perceptions of parents and professionals. *Journal of Intellectual Disability Research*, 24(4), 559-583. <https://doi.org/10.1177/1744629519829965>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.



Support needs of parents with intellectual disabilities: Systematic review on the perceptions of parents and professionals

Joyce Koolen

Avans University, Academie
Social Work, The Netherlands

Wietske van Oorsouw

Tranzo, TSB, Tilburg University,
The Netherlands

Lisbeth Verharen

HAN University of Applied Sciences,
The Netherlands

Petri Embregts

Tranzo, TSB, Tilburg University,
The Netherlands

Journal of Intellectual Disabilities
2020, Vol. 24(4) 559–583

© The Author(s) 2019

Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1744629519829965
journals.sagepub.com/home/jid



Date accepted: 07 January 2019

Abstract

This review aimed to examine the perceptions of parents, professionals and informal network members regarding support needs of parents with intellectual disabilities (ID). In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement, five databases were systematically searched and 19 qualitative studies were reviewed using thematic analyses. No data were available on the perceptions of the informal social network. Data on parents and professionals were categorized in four themes (type of support, sources of support, conditions of successful support and characteristics of support members). Data from professionals did not refer to emotional support needs or to the potential support of volunteers, friends and neighbours. Data from parents indicated a preference to be treated as 'full' parents, whereas professionals tended to focus on disabilities of parents. Results and implications contribute to insights into support needs of parents with ID from different perspectives and may help identify new entry points to improve future interventions and working alliances.

Keywords

intellectual disabilities, parents, perceptions, professionals, support needs

Corresponding author:

Wietske van Oorsouw, Department of Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University,
Postbus 90153, 5000 LE Tilburg, The Netherlands.

Email: w.m.w.j.vanoorsouw@uvt.nl

Introduction

Raising children is a challenge for the responsible caregivers (Calderon and Greenberg, 2010; Kazak, 1989; Ungar, 2009) and this challenge also applies to people with intellectual disabilities (ID). In addition to this generic challenge, people with ID are confronted with limitations in their cognitive abilities and adaptation skills and, therefore, depend (to a greater or lesser extent) on the support of others in their daily life (e.g. Embregts, 2011; Forrester-Jones et al., 2006; Hastings and Remington, 1994; Schalock, 2004; Van Asselt-Goverts et al., 2013).

According to the UN Convention on the Rights of Persons with Disabilities (United Nations [UN], 2006), exercising their rights regarding family life should be supported. This recognition has effected a sociocultural shift in the position of people with ID and changed the focus of studies regarding the parenthood of people with ID (Schuengel et al., 2017). A focus on the *capacity* of parents with ID is decreasing in favour of an increased focus on the *contextual models* of parenting (Schuengel et al., 2017). Parents with ID depend on the support of their social network; this support is crucial, since low parental support is directly related to the well-being of both parents and children, as well as to the developmental outcomes of children (Darbyshire and Stenfort Kroese, 2012; Llewellyn and Hindmarsh, 2015; Mayes et al., 2008; Wade et al., 2011). Also, vice versa, adequate support is considered important to improve parenting abilities and keep their families together (e.g. Aunos and Pacheco, 2013; Booth and Booth, 1999; Darbyshire and Stenfort Kroese, 2012; Llewellyn, 1997). Moreover, within child protection proceedings, the children of parents with ID are still significantly over-represented (Goodinge, 2000; Llewellyn and Hindmarsh, 2015) and, once they encounter the child protection system, the children of parents with ID are at risk to be removed from the care of their parents (Collings and Llewellyn, 2012).

Thus, focus has shifted from the capacity of parents with ID to the later evidence showing that people with ID can become competent parents (Collings and Llewellyn, 2012). However, the question regarding how to become a competent parent is inextricably linked to the support needs of parents with ID. In this context, support needs concern more than merely a description of the need for a particular type of support, and also concern 'who' should deliver this support and 'how' (Thompson et al., 2009). It is important to know *what* adequate support should consist of for this specific group to optimally shape working alliances with formal/informal network members and to improve the development of a broad range of parenting skills (e.g. Feldman, 1994; Meppelder et al., 2014). More insight into the support needs of parents with ID will help to further optimize parental support and increase successful parenting of parents with ID in the future.

Regarding parents with ID, describing these support needs can be complicated as they are generally diverse and often change over time (Tarleton et al., 2006). Moreover, in identifying support needs, not only the perceptions of the parents with ID themselves, but also the perceptions of professionals and informal network members are relevant. Despite close collaboration with formal/informal network members, the support needs of parents with ID are not always met (Llewellyn, 1997) and parents with ID indicate that the support offered is not always helpful (Stenfort Kroese et al., 2002). Therefore, putting the parent's perceptions of their support needs central, and viewing the perceptions of professionals and informal network members while keeping the parents' view in mind, might help in this respect.

This study aimed to systematically review the perceptions of parents, professionals and informal network members regarding the support needs of parents with ID. The goal was to increase insight into the support needs of parents with ID from different perspectives, and find new entry points that may help improve future interventions and working alliances. After careful

consideration, the authors decided to focus only on the synthesis of qualitative studies, to provide a better understanding and explanation of the possible depth and complexity of these experiences. This type of aim is not always captured in a quantitative meta-analysis (Walsh and Downe, 2005).

Methods

Search strategy

In accordance with the PRISMA statement (Liberati et al., 2009), a literature search was conducted using five databases, that is, medical (PubMed, CINAHL) and psychological literature (PsycINFO), and included all journals concerned with people with ID (Proquest and Web of Science). First, search terms referring to '*parents*' (i.e. parent, mother and father) were combined with search terms referring to '*ID*' (i.e. intellectual disab* OR develop* disab* OR develop* delay*, OR mental retard* OR learning difficult* OR intellectual limitation* OR cognitive disab* OR intellectual disab* OR learning disab* OR learning disorder). Then, three elements (i.e. population, exposure and outcome) of the PICO approach were used (as indicated in the PRISMA statement; Liberati et al., 2009) to achieve an accurate and structured selection of studies during the screening, eligibility and inclusion phase.

In this review, *population* refers to parents with ID, their professionals and their informal network members. Professionals included direct support staff in specialized ID services and direct support workers in general community settings (e.g. social workers, community nurses, lawyers). Excluded were professionals who were not in direct contact with parents (e.g. managers, policy-makers and politicians). Informal network members concerned family members (i.e. partners, siblings, parents) and acquaintances (i.e. friends, colleagues, neighbours). The *outcome* of studies referred to perceptions of service needs concerning the *exposure variable* 'parents with ID'.

Study selection

The selection process consisted of identification, screening, eligibility and inclusion (Figure 1). The first step in the selection process focused on the exposure of studies and searched the databases for records containing '*parents*' and '*ID*'. This broad first step was preferred in order to identify records on '*parents with ID*', since not all databases were able to process search terms including more than one word. Consequently, a broad range consisting of 7300 articles was selected.

To merge data, two researchers independently reviewed the titles and selected 887 records that focused on parents with an expected presence of ID. This means that not only titles that clearly referred to parents with ID were included, but also all titles that referred to parents with an increased risk of ID (e.g. with epilepsy or autism, due to frequent co-morbidity with ID). Most of the excluded records focused on parents of children with ID rather than on parents with ID themselves. Next, the following were excluded: duplicates ($n = 379$), conference abstracts ($n = 79$), publications outside the period January 1995 through January 2016 ($n = 70$), book chapters ($n = 27$), reviews ($n = 23$), book reviews ($n = 18$), references not published in English ($n = 6$), books ($n = 5$) and dissertations ($n = 5$). Finally, 275 papers remained.

The second phase of screening involved title and abstract selection by two independent reviewers (JK [PhD student] and WvO [PhD, experienced in conducting systematic reviews]) based on three inclusion criteria: (1) participants were parents with ID, their professionals or informal network members (note: professionals and informal network members had direct

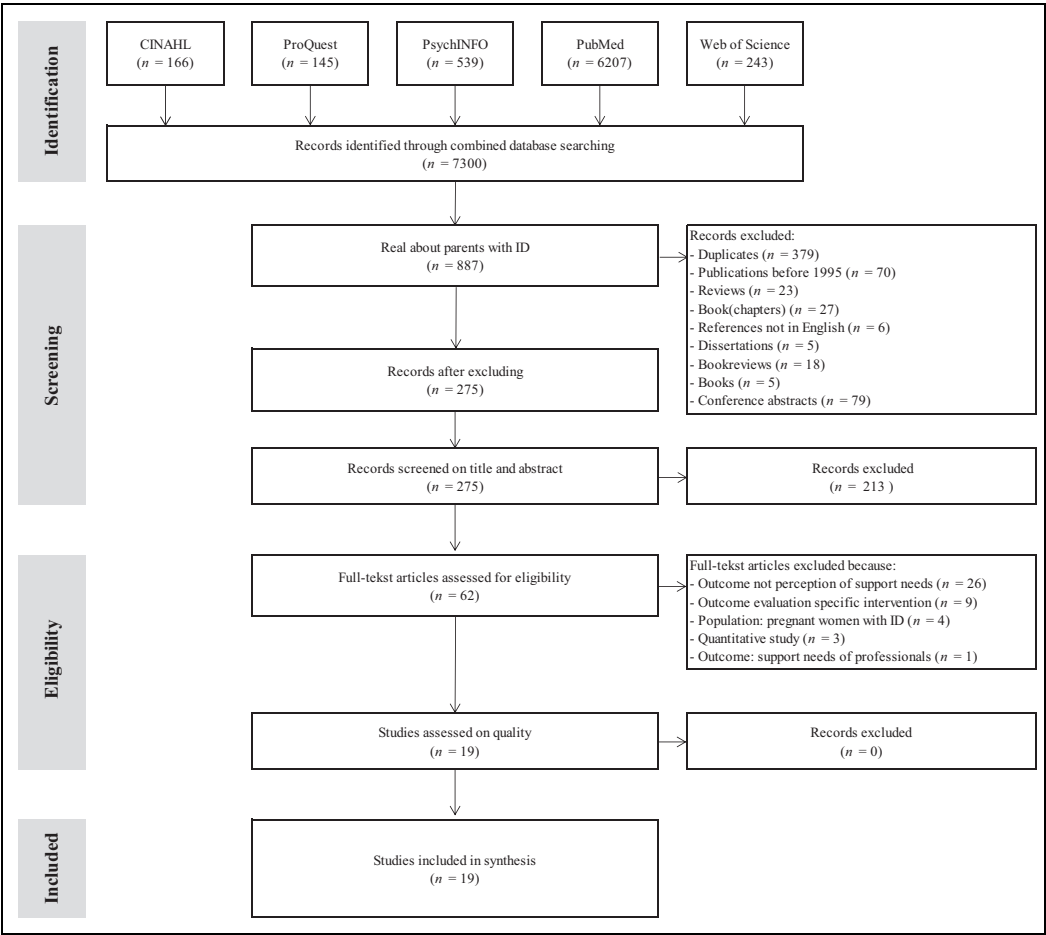


Figure 1. Flow chart of the literature selection process.

interactions with parents with ID, see search strategy); (2) outcomes included perceptions on the support needs of parents with ID; and (3) studies were *qualitative* or used a mixed-method format (Table 1). In this phase, the reviewers included all papers that (based on title and abstract) could possibly meet the inclusion criteria; for example, participants at increased risk for ID (e.g. participants with autism) were still included until further decisive information in the full-text phase was found. Only papers that clearly failed to meet the inclusion criteria (e.g. studies with managers in ID care) were excluded. In case of disagreement, two additional reviewers (LV and PE [both experienced in conducting systematic reviews]) were consulted, and the disagreements were discussed until consensus was reached. Of the 275 papers, 62 articles were selected to continue to the full-text phase.

During the eligibility phase, the content of full-text papers was first reviewed by two researchers (JK, WvO) who discussed the presence of inclusion/exclusion criteria (Table 1). Second, minimum research quality was assessed independently by the same two reviewers. Again, in case of

Table 1. Inclusion and exclusion criteria applied in the present study.

Inclusion criteria

Participants:

- Studies focusing on parents with ID, their support professionals or members of their informal social network. Note: professionals and informal network members had direct interactions with parents with ID.

Exposure and outcome:

- Studies with outcomes that included perceptions of the support needs of parents with ID

Methodology:

- Study results had a qualitative or mixed-method format

Exclusion criteria

Participants:

- Studies with a mixed sample of parents with ID, their support professionals and/or members of their informal social network were excluded when: (a) separate results were not provided for the different subgroups.
- Studies in which the sample included pregnant women with ID who were not yet a mother. Based on the aim of this review, we focused on the support needs that people experience from the moment they gave birth to a child.
- Studies focusing on perceptions of (nursing) students
- Studies focusing on (lay) community members who did not have any contact with people with ID

Exposure:

- Studies focusing on disability in general (i.e. without reference to intellectual disability)
- Studies focusing on specific disabilities not necessarily related to ID (e.g. acquired brain injury, physical disability, deafness)

Outcome:

- Studies focusing on the prevalence, description, and availability of different types of support (instead of perceptions regarding what is needed)
- Studies that aimed to evaluate the effectiveness of parenting interventions
- Studies focusing on training needs of support professionals or informal network members

Methodology:

- Studies not presenting empirical research data
- Studies presenting only psychometric data (i.e. validity and reliability of measures)

ID: intellectual disabilities.

uncertainty, two additional reviewers (LV, PE) were consulted. The reviewers used the Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011); this tool was designed to assess the methodological quality of relevant mixed-method papers selected for a systematic literature review. In addition to the first two general screening criteria that apply to several kinds of research designs, the MMAT contains a specific set of four criteria to assess the methodological quality of qualitative studies (e.g. ‘*Is the process for analyzing qualitative data relevant to address the research question?*’ and ‘*Is appropriate consideration given to how findings relate to the context, e.g. the setting, in which the data were collected?*’). The MMAT has demonstrated good content validity (Pluye et al., 2009). Pace et al. (2012) considered the MMAT inter-rater agreement of criteria to be moderate-to-perfect, and substantial regarding the overall quality score. Before screening, the present authors agreed that only studies with a negative score on both the MMAT screening questions or a negative score on all of the five MMAT quality criteria for qualitative

design would be excluded. However, all 19 studies remained on the basis of (at least) a minimum quality (Table 2).

Data extraction and analysis

General information concerned study characteristics (i.e. authors, country, topic, design) and participant characteristics (e.g. number of participants, gender). Thematic synthesis of the results (Thomas and Harden, 2008) was conducted to stay as close as possible to the accounts of the participants and researchers. First, the results sections were coded line-by-line by the first two reviewers. For each code, the reviewers indicated which perspective was concerned (i.e. parent, professional, informal network). For each sentence, at least one code and perspective was applied. When a new study was coded, these codes were added to the 'bank' of codes, and new codes were developed if necessary. Before completing this stage of synthesis, all codes and related text segments were examined by multiple authors to check for consistency of interpretation.

Second, the first two reviewers looked for similarities between the codes to group them into themes. To reduce bias, the four reviewers discussed and refined the codes and themes. Four themes (i.e. type of support, value of different support members, service conditions and characteristics of support members) emerged from the analyses and were used to structure the 'Results' section.

Results

Background and perceptions reported

Of the 19 studies, 9 were conducted in the United Kingdom, 5 in Australia, 2 in Sweden, 1 in Iceland, 1 in Germany and 1 in New Zealand; 16 studies had a qualitative design and 3 had a mixed-method design of which only the qualitative results sections were included. Table 3 provides an overview of the sample characteristics (e.g. marital status of parents, number of children, living situation) in each study. Fifteen studies considered the perceptions of parents (i.e. primarily mothers); a total of 200 parents with ID participated in the selected studies. One study ($n = 32$ participants) did not specify gender (Wade et al., 2007). Of the remaining 168 participating parents, 143 (85.1%) were female. Six studies included the perceptions of professionals; a total of 81 professionals participated in the selected studies. None of the remaining studies included data on the perceptions of informal network members. However, this does not imply no studies with informal network partners exist, or were not initially selected. Studies on informal network members did not remain in the present selection due to the lack of concrete data/information that could beyond doubt be linked to the perceptions of this unique target group.

Theme 1: Type of support

Perceptions of parents. Parents mentioned various types of support. Many articles reported the need for help with concrete childcare, for example, dressing (Stenfert Kroese et al., 2002; Wilson et al., 2013), bathing (Stenfert Kroese et al., 2002; Wilson et al., 2013) and feeding (Stenfert Kroese et al., 2002; Tarleton and Ward, 2007). Also, child-related housekeeping was mentioned (e.g. washing clothes and cooking meals), as well as child raising (e.g. setting boundaries, playing, homework and sexual education of older children; MacIntyre and Stewart, 2012; Pixa-Kettner, 1999; Starke, 2010; Stenfert Kroese et al., 2002; Wade et al., 2007).

Table 2. Characteristics of the included studies and summary of findings.

Author/year/ country	Topical focus	Stated method	Sample description	Theoretical approach to data analysis	Main themes, or a summary of main findings (when themes not utilized)
Booth and Booth (2005) United Kingdom	Provided an experiential account of care proceedings from the perspectives of mothers and fathers with learning difficulties.	Semi-structured interviews	22 parents with ID (18 mothers and 4 fathers)	Type of analysis not specified	Five themes were described: parents' views on assessment; support case conferences; core group; review and other meetings; Court proceedings: the aftermath.
Booth and Booth (2006) United Kingdom	Let mothers with ID describe their experiences of the child protection system in their own words.	Open unstructured interviews	3 mothers with ID	Narrative approach	There were two distinct plot lines. First, there was the parent's voice, referring to an individual or couple's unique personal narrative that makes each and every story different. Second, there was the parent's voice, referring to the generic elements or commonalities that bound their accounts together as stories of a kind that all engage with one overarching theme: what it is like as a mother with learning difficulties to have one's competence as a parent placed under scrutiny by the state.
Conder et al. (2008) New Zealand	Utilized findings on parents with ID in order to outline their experience of having children out of home.	Semi-structured interviews	19 parents with ID (13 mothers and 6 fathers)	General inductive approach	The main findings were: parents with ID need to be supported to maintain meaningful relationships with their children; parents with ID and foster parents need to develop positive ways of working together; parents with ID and foster parents need ongoing support from a social worker to develop and keep a positive relationship between them.
Gould and Dodd (2014) United Kingdom	Explored some of the issues experienced by mothers who lost custody and how services might help these women adjust to their loss.	Semi-structured interviews	9 mothers with ID	Interpretive phenomenological analysis	Three superordinate themes were described: <ul style="list-style-type: none"> • Suitable to be a mum • Responses to removal • Power

(continued)

Table 2. (continued)

Author/year/ country	Topical focus	Stated method	Sample description	Theoretical approach to data analysis	Main themes, or a summary of main findings (when themes not utilized)
Jones (2013) United Kingdom	Experiences of social workers; what practice issues and dilemmas working with parents with ID presents	Semi-structured interviews	6 social workers	'Data were coded or categorised manually' (p. 175).	Three themes were described: <ul style="list-style-type: none"> • Emotional impact • Values and attitudes • Barriers
Llewellyn (1995) Australia	Explored views of parents with ID about their relationships and social support for their parenting.	Semi-structured interviews; field notes; participant observation	12 parents with ID (6 mothers and 6 fathers)	Grounded theory approach	The main findings were: <ul style="list-style-type: none"> • Most emphasis placed on support received from spouses and partners. • Support was not always viewed as beneficial. • Parents exhibited a preferred sequence in seeking help.
Mayes and Llewellyn (2012) Australia	Described the daily lives of mothers with ID who lost custody.	Semi-structured interviews	7 mothers with ID	'The goal of data analysis was to uncover the plots within the data that held the story together and gave meaning to the story being told' (p. 124).	Three distinct narratives were described: <ul style="list-style-type: none"> • Living as the mother I am • Living as the mother I should be • Not feeling like a mother anymore
McConnell et al. (1997)	Views of specialist service providers on parents' support and service needs.	The 40 participants took part in one focus group or interview of which there were 9 and 4.	40 specialist service providers	Thematic analysis	Three key categories were described: <ul style="list-style-type: none"> • Parents' special needs • Desirable service characteristics • Constraints on service delivery

(continued)

Table 2. (continued)

Author/year/ country	Topical focus	Stated method	Sample description	Theoretical approach to data analysis	Main themes, or a summary of main findings (when themes not utilized)
McGhee and Hunter (2011) United Kingdom	Explored (1) the capacity of children's hearing processes considering the needs of parents with ID; and (2) whether the non-adversarial tribunal provides a constructive arena to facilitate greater dialogue between parent and child welfare decision makers.	Semi-structured interviews with parents with ID, child reporters, and lawyers; focus group with tribunal decision makers.	7 parents with ID (6 mothers and 1 father), 3 child reporters, and 4 lawyers	Thematic analysis	Seven themes were described: <ul style="list-style-type: none"> • Recognizing learning disabilities • Pre-hearing • Contesting grounds of referrals • Participation • Decision-making • Advocacy and representation • Court versus hearings
MacIntyre and Stewart (2012) United Kingdom	1. Identified the needs of a small number of parents with a learning disability living in Scotland. 2. Explored the role of advocacy in assisting parents to have their needs met.	Mixed method for the qualitative part; in- depth interviews with parents with ID and advocates were also used. Additionally, key informant interviews with stakeholders were conducted.	For qualitative part: 5 mothers and 5 advocates; 4 stakeholders in the field. Only the data from mothers were used.	Thematic analysis	Seven themes were described: <ul style="list-style-type: none"> • Service demands • Complexity of individual situations • Support for parents and the individual and the early identification of support needs • Experience with the child protection service • Appropriate assessment • Joint working, eligibility criteria and funding • Advocacy
Pixa-Kettner (1999) Germany	A follow-up of parents with ID to see further development of certain cases of parenthood.	Semi-structured interviews	3 mothers with ID 2 couples with ID	Documentary interpretation	Summary of main findings: Parental responsibility seems to correspond with the kind of support received; Extensive support seems to work out badly.

(continued)

Table 2. (continued)

Author/year/ country	Topical focus	Stated method	Sample description	Theoretical approach to data analysis	Main themes, or a summary of main findings (when themes not utilized)
Starke (2010) Sweden	Clarified the basic views and experiences of mothers with ID regarding their interaction with the care and support practitioners they encountered in their everyday lives. Captured the views and experiences of professionals working with parents with ID.	Semi-structured interviews	7 mothers with ID	Thematic analysis	Three themes were described: <ul style="list-style-type: none">• Incomprehensibility• Support as empowerment• Understanding oneself as needing help
Starke (2011) Sweden		Focus group	19 support professionals (18 female and 1 male)	Quotations from the focus group transcripts (a total of 18 h of group discussions were recorded) were collected in which one or more of the terms 'parents', 'parenthood', 'parenting', 'childhood' and 'children' were featured. These were then combined and categorized accordingly, with the combinations of themes first reviewed internally and then compared with one another (p. 165).	Summary of main findings: When the child was living with the parents, parental limitations and an inability to meet the needs of their children were emphasized, with parents failing to recognize their own high support needs. When the child had been placed in out-of- home care, the parental role was seen as important, and it was considered vital to continue to provide proper support to enable the parents' ongoing contact with their child and maintain their parenting.

(continued)

Table 2. (continued)

Author/year/ country	Topical focus	Stated method	Sample description	Theoretical approach to data analysis	Main themes, or a summary of main findings (when themes not utilized)
Stenfert Kroese et al. (2002) United Kingdom	Investigated the impact of social support networks of mothers with ID on their psychological well- being and their views of parenting.	Mixed method; for the qualitative part, semi- structured interviews were used	15 mothers with ID	Thematic analysis for qualitative analysis	Themes in qualitative analysis: <ul style="list-style-type: none"> • Support that is helpful • Support that is unhelpful • Benefits of parenthood • Burdens of parenthood • Hopes for future
Strike and McConnell (2002) Australia	Represented the view of parents with ID regarding how supporters should listen and work together with parents with ID.	Semi-structured interview	1 parent with ID (male)	Type of analysis not specified	Summary of main findings: Supporters should listen and work together with parents with ID; supporters could teach parents with ID, and parents with ID can teach supporters
Tarleton and Ward (2007) United Kingdom	Located and described examples of positive practice in supporting parents with ID and their children in the United Kingdom.	Semi-structured interview	30 parents with ID (25 mothers and 5 fathers)	Thematic analysis	Ten themes were described: <ul style="list-style-type: none"> • Support to be good enough parents • Support in ways that parents wanted • Support to develop and learn skills • Help to overcome 'bigger problems' • Support to feel better • Support from each other • Support to develop self-confidence • Support to get their voices heard • Support to keep their children • Support to understand the court process
Traustadóttir and Sigurjónsdóttir (2008) Iceland	Examined the role of extended family members in assisting mothers with ID to keep and raise their children.	Participant observation; semi-structured interviews	18 mothers with ID professionals (<i>n</i> = not specified) Informal social network members (<i>n</i> = not specified). Only the data of mothers were used.	Based on grounded theory approach and hermeneutic methods	Summary of main findings: Assistance from extended family continues to be crucial in determining whether mothers with ID retain custody of their children. Female relatives referred to as 'mothers' played the most important role in supporting parents.

(continued)

Table 2. (continued)

Author/year/ country	Topical focus	Stated method	Sample description	Theoretical approach to data analysis	Main themes, or a summary of main findings (when themes not utilized)
Wade et al. (2007) Australia	Examined the helpfulness of service delivery to parents with ID by exploring the characteristics of services that parents say they found helpful and not helpful and the characteristics of the services they desired.	Mixed method; for the qualitative part semi-structured interviews were conducted.	32 parents with ID (the proportion of mothers and fathers is unknown)	Each parent response was either an indication of helpful or unhelpful service characteristics (helpfulness).	Summary of main findings: Parents find family-centred practices more helpful than professionally-centred practices, and participatory help more effective than relational help.
Wilson et al. (2013) United Kingdom	Explored the postnatal care experiences of mothers with an ID	Semi-structured interviews	6 mothers with ID	Interpretative phenomenological analysis	Two superordinate themes and seven subthemes were described. Superordinate themes were: <ul style="list-style-type: none"> Challenges of providing support How support was delivered Subthemes were: <ul style="list-style-type: none"> Significance of family support Feeling supported by professionals Professional input as an intrusion Managing unhelpful supports Feeling 'told what to do' Feeling judged Significance of feeling understood

ID: intellectual disabilities.

Table 3. Sample characteristics of included studies.

Author(s) (year)	No. of parents with ID	No. of children	Marital status	Age child(ren)	Child(rens) living situation
Booth and Booth (2005)	18 mothers 4 fathers	53 children in total over 20 households	–	49 children (ages unknown) + 4 adult children	4 adult children lived on their own; 13 children lived with parents (6 were involved in care proceeding; 7 were never subject to care application); 16 were fostered; 23 had been adopted; 1 lived in a children's home.
Booth and Booth (2006)	3 mothers	Resp. (1) 1 child; (2) 4 children and pregnant (mother wants to be sterilized after birth); (3) 2 children	Resp. (1) No information about partner; (2) With partner who lives on the other side of town; (3) Lives alone, no information about partnership.	Resp. (1) Age unknown; (2) 1, 2, 4 and 14 years; (3) Ages unknown.	All children were involved in care proceedings/child protection process. Resp. (1) Child lived at home with mother; (2) One child lived with mother's brother. 3 children were adopted. Expected baby will be removed at birth according to social services plans; (3) One child in foster care. 1 child was adopted.
Conder et al. (2008)	13 mothers 6 fathers	–	Most parents were single, few were married.	–	12 parents had children in foster care. Most parents had one child in foster care. One parent had four in foster care and one child in residential care.
Gould and Dodd (2014)	9 mothers	1 × 1 child; 4 × 2 children; 3 × 3 children; 1 × 4 children	4 lived with partner (3 married, 1 cohabiting); 3 lived on own (single); 1 stayed in a family placement scheme (divorced), 1 lived with carers (single).	–	At least one child was removed and had no face-to-face contact with their child/ children since they were removed. Resp. (1) 1 adopted and 1 lived at home; (2) 1 lived independently, 1 adopted, 1 in residential home; (3) 1 lived with father and 2 adopted; (4) 2 adopted and father lived at home; (5) 1 adopted; (6) 1 adopted and 2 lived at home; (7) 2 adopted; (8) 2 adopted; (9) 2 adopted by aunt and uncle.

(continued)

Table 3. (continued)

Author(s) (year)	No. of parents with ID	No. of children	Marital status	Age child(ren)	Child(rens') living situation
Jones (2013)	No parents involved. Six female professionals were working in a local authority family centre.				
Llewellyn (1995)	6 couples. In all couples (except 2) both parents had ID.	3 × 1 child; 3 × 2 children.	All had a partner, 5 were married.	Resp. (1) 18 months and 3 years; (2) 4 years; (3) 5 years; (4) 14 and 12 years; (5) 4 and 7 years; (6) 22 months	Parents were primarily responsible for parenting their children. Children were not permanently removed.
Mayes and Llewellyn (2012)	7 mothers	1 child; 2 children; 3 × 3 children; 2 × 5 children.	—	Resp. (1) 3 years; (2) 2, 9, 12, 13 and 14 years; (3) 3 and 6 years; (4) 2, 3 and 5 years; (5) 9 months, 3 and 5 years; (6) 2, 6, 9, 10 years (twins); (7) 3, 9, 10, 13 years.	Children were removed via statutory child protection proceedings.
McConnell et al. (1997)	No parents involved. Forty specialist service providers in five metropolitan and three rural areas. Sample consisted of 10 case workers, 9 district officers, 16 therapists, 3 psychologists, 1 branch manager, and 1 assistant manager. All participants were experienced in working with people with ID.	17 children in total	—	—	5 Children were living at home with a parent, 12 children were in alternative care provision
McGhee and Hunter (2011)	6 mothers 1 father Also: 3 child reporters, and 4 lawyers				

(continued)

Table 3. (continued)

Author(s) (year)	No. of parents with ID	No. of children	Marital status	Age child(ren)	Child(rens) living situation
MacIntyre and Stewart (2012)	5 mothers referred for advocacy support following child protection proceedings.	1 × 4 children; 3 × 2 children; 1 × 1 child	1 × married; 1 × single; 1 × partner in prison (no contact); 1 × single and widowed; 1 × lives alone, has partner who lives with his own parents. Additional information: participants lived in fairly poor housing conditions and experienced poverty. 3/5 experienced sexual and physical abuse or financial exploitation in the past.	Resp. 3 married adults (ages unknown) and one child of 13 years; 3 and 7 years; 13 and 11 years; 2 × ages unknown; 2 years	Resp. (1) Youngest son lives at home with mother and husband. Three adult children are married and live on their own; (2) both children in foster care; (3) both children in foster care; (4) one child had left home, one child is accommodated by the social work department; (5) child in foster care since birth
Pixa-Kettner (1999)	5 mothers	3 × 1 child; 1 × 2 children; 1 × 3 children	(1) Married, husband worked and lived far away. Only at home in the weekends. Mother later on divorced. (2) Married (3) Single, no contact with father of child (4) Married, lived separate from (alcohol) addicted husband (5) Married	Precise ages unknown; about 3 years; 3 years; 5 and 9 years; 1 year	(1) Children lived at home with mother and grandmother. The oldest two children were given to a foster home after their grandmother died. The youngest child lived with mother with mother's sister and her children. (2) Parents moved into an institution shortly before their child was born. (3) Child lived with grandmother; mother could come over whenever she wanted to. (4) Children live with mother. Mother gained the care and custody of her children after court battle. (5) Child lives with father and mother in an apartment.

(continued)

Table 3. (continued)

Author(s) (year)	No. of parents with ID	No. of children	Marital status	Age child(ren)	Child(rens) living situation
Starke (2010)	7 mothers (aged 24–42 years)	14 children in total	1 × married, living with husband and children. 5 × single.	From 2–15 years	Two children live with mother and father; one child lived with mother and grandmother, one child lived with mother and mother's grandmother; one child was taken care of by the foster family in which the mother had grown up herself; two children did not live with their mother (i.e. out of home care), one child lived with his/her mother
Starke (2011)	No parents involved. 19 support professionals (18 women) working in urban locations ranging from a town with 24,000 inhabitants to a major regional centre with a population of more than 500,000. As social workers, special pedagogues and psychologists, they worked for a range of municipal agencies, including social service departments and special schools, and for regional authorities, including regional child and adult habilitation services and a guidance centre for young people				
Stenfert Kroese et al. (2002)	15 mothers (aged 25–49 years)	8 × 1 child; 1 × 2 children; 4 × 3 children; 2 × 5 children	8 × married; 4 × cohabiting; 2 × single; 1 × separated	2 years; 2 years; 14 years; 10 years; 9 and 17 years; 1, 5 and 6 years; 1 year; 4 years; unknown age; 2 years; 4 years; 10, 13 years; 14 years; 6 years; 1 year; <1, 2, 5, 7 and 8 years	22 children living with parent, all other children in care of services
Strike and McConnell (2002)	1 father	3 children	married	6, 9, 11 years	Children live at home with help of a family support worker
Tarleton and Ward (2007)	25 mothers, 5 fathers (aged 20–50 years)	–	–	–	Not all children lived with parents. All of the parents whose children still lived with them, were receiving support to help them engage positively with services and to fulfil their parenting responsibilities to the best of their ability.

(continued)

Table 3. (continued)

Author(s) (year)	No. of parents with ID	No. of children	Marital status	Age child(ren)	Child(rens) living situation
Traustadóttir and Sigurjónsdóttir (2008)	10 mothers (aged 25–83 years) and 8 mothers (in a 2nd project) (same age range as the youngest mothers in the previous study)	20 children in total 18 children in total	–	(1) Children of elderly mothers and middle-aged; (2) children of middle-aged mothers were teenagers and young adults; (3) children of young mothers were of preschool and school age	Three of the mothers in the two older generations lost custody of their children while all five younger mothers had kept their children. 11/18 children had been removed from the parent's care
Wade et al. (2007)	32 mothers and fathers (mainly consisting of mothers) Aged >18 years and were primary carers of one or more children	–	–	Ages 0–18 years	All parents had at least one child living with them and all were receiving at least one service from a government of non-government agency.
Wilson et al. (2013)	6 mothers (aged 22–55 years)	Total number of children ranged from 1 to 8.	2 × single; 4 × married and living with partner	Ages ranged from 10 weeks to 15 years	All had one or more children being removed by child protection agencies.

ID: intellectual disabilities; –: information not available.

Similarly, parents needed support to deal with services. That is, help to understand and join meetings (e.g. one father mentioned: 'support to understand doctors'; Strike and McConnell, 2002: 57 and one mother said: 'Barbara [community nurse] went to court with me and wrote everything down, told me what to say, and told me to keep my gob [mouth] shut in court'; Tarleton and Ward, 2007: 199). Parents also needed support to deal with procedures (e.g. filling in forms) (Booth and Booth, 2006). Moreover, many quotes referred to receiving money and materials from supporters, such as 'money for nappies' and 'gave me a phone' (Stenfert Kroese et al., 2002: 333). Less frequently, parents indicated to need help with financial management skills, such as saving and spending money (Stenfert Kroese et al., 2002; Tarleton and Ward, 2007; Wade et al., 2007).

Furthermore, parents needed emotional support, described in terms like: 'worry over me' (Stenfert Kroese et al., 2002: 333), 'give a shoulder to cry on' (Wilson et al., 2013: 593) and 'having someone on my side' (McGhee and Hunter, 2011: 261). Parents identified the need to be unburdened, for example, by a supporter who babysits (Booth and Booth, 2006; Stenfert Kroese et al., 2002), or someone who spoils the kids by taking them out (Stenfert Kroese, 2002). Finally, three articles mentioned needs regarding disability awareness, for example, understanding of limitations, becoming better in receiving help (Llewellyn, 1995; Starke, 2010; Wilson et al., 2013).

Perceptions of professionals. Only two studies described the perceptions of professionals regarding different types of support; however, neither of these studies referred to possible emotional support needs of parents. Professionals mentioned help with cooking and needs regarding child raising like setting boundaries, disciplining the children and stimulating to play (McConnell et al., 1997). Furthermore, professionals indicated that supporters helped parents to contact services, or 'refer parents to services' and 'introduce parents to agencies' (McConnell et al., 1997: 9). Also, needs regarding budgeting and shopping were mentioned (McConnell et al., 1997). Finally, Starke (2011) mentioned needs regarding disability awareness by explaining: 'of great importance was that these parents were aware of their limitations and of the kind of consequences that the ID had on their everyday life' (Starke, 2011: 168).

Theme 2: Sources of support

Perceptions of parents. Parents valued the role of family members (especially mothers) and partners regarding practical childcare and emotional support. For example, one parent described: 'It was nice to have two close people [mother and partner] there. That meant so much to me' (Wilson et al., 2013: 594). Moreover, parents considered family members to be the best alternative to/protection from foster care (Conder et al., 2008; Traustadóttir and Sigurjónsdóttir, 2008). Three studies indicated the moral support that parents received from other parents in similar situations (Llewellyn, 1995; Tarleton and Ward, 2007; Wilson et al., 2013). Although less frequently, friends, neighbours and volunteers were mentioned as a source of (mainly practical) support (Llewellyn, 1995; Stenfert Kroese et al., 2002; Wilson et al., 2013).

According to parents, formal network members also had a role. Most frequently mentioned were 'advocates', who represent parents in court to ensure their voice is heard (Booth and Booth, 2005, 2006; Gould and Dodd, 2014; McGhee and Hunter, 2011; MacIntyre and Stewart, 2012; Starke, 2011; Tarleton and Ward, 2007), to help them keep their child (Booth and Booth, 2005; Tarleton and Ward, 2007), and to maintain contact with children in case of foster care (Conder et al., 2008; Gould and Dodd, 2014; McConnell et al., 1997; Mayes and Llewellyn, 2012; Starke, 2011; Stenfert Kroese, 2002; Strike and McConnell, 2002). The practical and emotional support of

social workers was also frequently mentioned (Pixa-Kettner, 1999; Starke, 2010; Strike and McConnell, 2002; Tarleton and Ward, 2007). For example, one parent said: 'Tracey [support worker] helps me sort out kids' clothes that are too small . . . and to throw out food that is out of date' (Tarleton and Ward, 2007: 197). Finally, support of psychologists and healthcare staff (in particular midwives) was mentioned by parents, especially with respect to post-birth for practical guidance, advice and emotional support (Wilson et al., 2013).

Perceptions of professionals. Only three studies reported perceptions of professionals regarding the involvement of different network members; all three mentioned advocates to ensure that the voice of parents was heard and to maintain contact with children in case of foster care (McConnell et al., 1997; McGhee and Hunter, 2011; Starke, 2011). Besides advocates, professionals identified grandparents as being a crucial safety net (McGhee and Hunter, 2011). One professional stated: 'I think if somebody has very marked learning difficulties and the grandparents [parents of the parents] are not stepping up to the plate then those children are likely to go to foster care' (McGhee and Hunter, 2011: 260). Contact with other parents was considered supportive (McConnell et al., 1997). Professionals recognized the important contribution of social workers in the everyday lives of parents (McConnell et al., 1997; Starke, 2011). As one professional mentioned: 'A lot of the time they [parents] are isolated . . . With such isolated parents, service providers took on a role that might otherwise be provided by a mother, grandmother, friend, or neighbour' (McConnell et al., 1997: 9). Not described in any of the studies were: professionals' perceptions regarding the role of partners, other family members besides grandparents, health professionals such as midwives, and informal network members.

Theme 3: Conditions of successful support

Perceptions of parents. Variables that contribute to successful support were described in eight different studies; specifically, parents indicated that services should always offer the possibility of 'someone being available' (Booth and Booth, 2006: 116). Support is preferably long-term and ongoing (Tarleton and Ward, 2007; 'continuous case management', Wade et al., 2007: 93), and tailored to individual needs ('help that was a good fit with their own perceptions of their needs', Llewellyn, 1995: 357; Wilson et al., 2013).

Perceptions of professionals. According to professionals, variables that contribute to successful support were reported in three studies. In summary, services should always be available (Starke, 2011), structured, long-term/ongoing (McConnell et al., 1997), proactive, at home and tailored to individual needs (Jones, 2013; 'work where they are at', McConnell et al., 1997: 3). As one professional noted: 'If we can provide ongoing support . . . we can avoid a crisis in the future' (McConnell et al., 1997: 10).

Theme 4: Characteristics of support members

Perceptions of parents. Six studies mentioned the personal strengths of support members. Parents identified the need for a supporter who is honest and straight. As one parent noted: 'When you explain something, get straight down to the nitty gritty. Don't waffle on. You'll get more things done that way and there is less chance of confusion' (Strike and McConnell, 2002: 60). Supporters also need to be available/accessible when needed (Booth and Booth, 2005; Wilson et al., 2013), convey understanding and not patronize (Booth and Booth, 2006; Tarleton and Ward, 2007), and

be friendly and helpful (Booth and Booth, 2005, 2006; Wade et al., 2007). One mother said: 'I need somebody who's very understanding and will sit there and listen' (Booth and Booth, 2006: 97).

Parents pointed to the fact that supporters need to have trust in their ability to be good parents (Tarleton and Ward, 2007). Parents wanted supporters to look at what they actually observe and not jump to conclusions based on written files (Strike and McConnell, 2002). One father said: 'You should recognise them [parents] as a person first. If you can get away from the label and concentrate on the individual, you will find the individual will help you, then you can help them' (Strike and McConnell, 2002: 58). The importance of listening was mentioned frequently and expressed in many different ways: for example, listen to me, sit there and listen, listen and don't interrupt, show that you [supporter] are listening, listen with an open mind, and have someone to listen (Booth and Booth 2005, 2006; McGhee and Hunter, 2011; Strike and McConnell, 2002; Tarleton and Ward, 2007; Wade et al., 2007; Wilson et al., 2013).

Parents wanted supporters to ask what they want (Strike and McConnell, 2002; Tarleton and Ward, 2007) and make sure parents understand what is happening. Therefore, supporters could break down the tasks (Booth and Booth, 2005; Llewellyn, 1995; Tarleton and Ward, 2007) and explain (Booth and Booth, 2005, 2006; Tarleton and Ward, 2007). One mother said: 'If I didn't understand, my solicitor put it in shorter sentences and explained it more clearly' (Booth and Booth, 2005: 122). Supporters could also show what to do (Tarleton and Ward, 2007; Wilson et al., 2013) and give advice instead of taking over (Starke, 2010; Stenfort Kroese et al., 2002). One parent noted: 'People like to interrupt and say "I'll do it for you" and that is not right . . . do it together'. (Strike and McConnell, 2002: 59). Studies also reported the importance of receiving positive feedback (Booth and Booth, 2006; Gould and Dodd, 2014; Llewellyn, 1995; Starke, 2010; Tarleton and Ward, 2007; Wilson et al., 2013) and making eye contact (Strike and McConnell, 2002).

Perceptions of professionals. According to professionals, supporters should be interested in the parent (Starke, 2011) and be honest and open about their roles (McConnell et al., 1997; Starke, 2011). The importance of accepting parents as they are was also emphasized (McConnell et al., 1997). For example, one professional stated: 'You've got to be careful to do the things that they [parents] see they need and not the things that you [supporter] see they need . . . you've got to work with them where they are at and not want to change everything'. Jones (2013) mentioned the value of reciprocal relationships between supporters and parents by quoting: 'You're asking people to share the deepest darkest moments of their lives with you and, in any relationship, you have to give a little bit back as well' (Gould and Dodd, 2014: 177). Studies reported the importance of an atmosphere of receiving positive feedback to build up self-esteem/confidence (Gould and Dodd, 2014; McConnell et al., 1997). The following illustrates how one case worker perceived this: 'I try to get them to feel confident that they can do it' (McConnell et al., 1997: 9).

Furthermore, four articles reported that, according to professionals, supporters preferably involve parents, ask what needs they have and ensure information is understood (McConnell et al., 1997; Starke, 2011). Therefore, a variety of communication skills are suggested: supporters break down tasks, listen to parents' opinions, simplify explanations (e.g. of hearing decisions), use one-syllable words, explain why things are as they are, take into account reading ability, use repetition, demonstrate skills and teach skills instead of doing things for them (McConnell et al., 1997; McGhee and Hunter, 2011; Starke, 2011). As one service worker noted: 'It is not enough just to explain it, you have to say try this, try that . . . actually demonstrate it in that situation' (McConnell et al., 1997: 11).

Discussion

This study aimed to review the support needs of parents with ID as perceived by the parents themselves, their professionals and their informal network members. Unfortunately, none of the identified studies reported the perceptions of informal network members. This might be related to methodological aspects of the present study (see 'Limitations' section below), or may be due to underestimation of the value of the informal network members. Focus on the full role of both formal and informal network members is in progress (e.g. Mayes and Llewellyn, 2012) and may not yet be fully represented in study samples. Moreover, there were far fewer studies on the perceptions of professionals compared to studies on the perceptions of parents. The perceptions of parents mainly concerned data derived from mothers, whereas the perceptions of fathers were under-represented. Also under-represented were studies on parents with ID who have school-age or adolescent children; however, this information is valuable since support needs change as children get older. Finally, the reported experiences were mainly derived from middle-class parents living in Western countries. This distribution should be taken into account, implying that looking for clear (dis)agreements between, for example, parents and professionals, would not be appropriate. Nevertheless, the present results reveal four apparently relevant implications for research and practice.

First, the potential support of volunteers, friends and neighbours was not mentioned in the studies on professionals. Although these studies recognized the valuable role of informal network members, the variety of informal network members was small and mainly limited to the role of grandparents. However, such a limited reference is not unlikely, because the social network of people with ID consists mainly of professionals and family members (van Asselt-Goverts et al., 2015). Nevertheless, this does not mean that other members (e.g. volunteers, friends and neighbours) might not be willing or already support parents with ID in practice. This finding may help increase professionals' awareness of the fact that informal networks might consist of more (and a wider range) of people than initially estimated. If professionals succeed in identifying informal network members who (can) play a significant role in supporting parents with ID, professionals may have an opportunity to strengthen the involvement of an informal network. In cases of (perceived) isolation of parents, professionals take on roles that might be better provided by a friend, neighbour and so on (McConnell et al., 1997) and, as a result, maintain the (perceived) absence of informal network members.

Second, studies on parents frequently referred to emotional support needs (e.g. 'a shoulder to cry on', 'worry over me'), underlining the need for emotional support. Remarkably, studies on professionals did not identify explicit needs that referred to emotional support. This difference might be related to the small sample of studies on professionals in the present review. However, the question arises as to whether parents and professionals have a similar (explicit) awareness of certain types of support needs. For example, parents mentioned different types of emotional support, whereas the professionals did not. On the other hand, professionals (like parents) focus on other types of support, such as help with cooking, child raising, contacting services, budgeting and disability awareness. Perhaps the presence of emotional support needs is so self-evident for professionals that they find it unnecessary to specifically mention this. Further research is needed to elucidate the possible implications of this finding for working alliances, mutual understanding and the communication between parents and professionals.

Third, data indicate that parents want their supporters to take them seriously as full parents. Although studies on professionals also mention this, the focus in studies on professionals was

mainly restricted to raising awareness regarding the limitations of parents with ID. A focus on limitations, rather than full parenthood, might be related to the prejudicial ideas that professionals have about the capabilities of parents with ID. Earlier studies reported that support staff are not always convinced of the ability of parents with ID to improve their parenting skills (e.g. Meppelder et al., 2014). Moreover, professionals might focus on limitations of the parents because of the responsibility they feel regarding the vulnerability and safety of the children involved (Jones, 2013). If professionals feel unsure about the parenting skills and tend to focus mainly on the limitations of parents with ID, it becomes difficult to meet the needs of parents to be (once and for all) taken seriously in their wish to be a full parent. Data from the present review have revealed this predicament. In their working alliances, it might be preferable for both parents and professionals to be open and honest about their worries (e.g. 'Can I trust in your ability to be a good parent and how should I support you in this?') and ambitions in becoming a full parent (e.g. 'Do you truly believe in me as a full parent and do we share my wish to keep my children away from foster care?'). Through explicit and clear communication, expectations might be adjusted, and possible gaps might be bridged.

Finally, data from this review show that parents and professionals seem to describe support needs in different ways. These results might be related to the (so-called) 'tension between concepts (abstract concepts) and conceptions (the concrete interpretation given to abstract concepts)' (Rawls, 1999). The conceptions that parents seem to use (e.g. the wide differentiation in descriptions about how to listen) at least underline the importance of particular support needs according to parents (e.g. the concept 'listen to parents'). Parents used a variety of concrete descriptions about how to act (i.e. conceptions; e.g. 'fill in forms', 'go to court with me', 'tell me what to say') whereas professionals tended to use less differentiation and perhaps even more abstract terms for the same needs (i.e. concepts; e.g. 'introduce parents to agencies'). Similarly, it is questionable whether the (only) description of professionals regarding the importance of listening (i.e. 'listen to opinions of parents') fully captures the meaning of the broad variety of descriptions of parents regarding how to listen (e.g. 'listen to me', 'sit there and listen', 'listen and not interrupt', etc.). Such stylistic differences might depend on methodological differences between the studies. However, successful alliances start with careful communication. Therefore, it is important that professionals acknowledge their possible tendency to think in concepts rather than conceptions. Variations on the following questions might help to explore each other's perceptions: What do we (parent and professional) mean by childcare-related support needs: Do you mean you need help with buying your kid's clothes, bathing the baby, cooking healthy meals or maybe all of this? What do we (parent and professional) mean by emotional support needs: Do you mean someone to be there and listen, to support you in dealing with your emotions, and so on? Such awareness might increase the fit between parents' wishes on the one hand, and the intentions and interpretations of the professionals on the other. Finally, this could positively contribute to parents feeling understood. The information embedded in the concrete descriptions of parents with ID in this review might serve as a useful entry point to improve practice, research and policy.

Limitations

The most important limitation of the present review is probably related to the lack of studies on informal network members after the study selection procedure. This was a systematic review, implying that the authors followed standardized procedures and strict criteria for the literature selection and the analyses. However, a consequence of this is that potential additional/valuable

information on the perceptions of informal network members might have been disregarded due to a lack of data that could, beyond doubt, be connected to participants from the informal networks of parents with ID. Nevertheless, the absence of data on the perceptions of informal network members in this review is in itself meaningful, but does not imply an overall lack of studies on informal network members of parents with ID.

Conclusion

This review included more studies on the perceptions of parents than on the perceptions of professionals, and none of the selected studies reported perceptions of informal network members. Nevertheless, insight into the unique perceptions of informal network members is definitely required to improve/extend both research and practice. The emerging data were categorized into four themes with perceptions on: (1) type of support, (2) sources of support, (3) conditions of successful support and (4) characteristics of support members. This review provides an up-to-date overview with relevant implications that increase insight into the support needs of parents with ID from different perceptions and may help identify new entry points to improve future interventions and working alliances.

Authors' note

Joyce Koolen and Wietske van Oorsouw contributed equally to the paper and, therefore, share the position of first author.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This project was supported by Avans University, Breda, The Netherlands.

References

- Aunos M and Pacheco L (2013) Changing perspective: workers' perceptions of inter-agency collaboration with parents with an intellectual disability. *Parents with Disabilities in Child Welfare* 7: 658–674.
- Booth T and Booth W (1999) Parents together: action research and advocacy support for parents with learning difficulties. *Health & Social Care in the Community* 7: 464–474.
- Booth T and Booth W (2005) Parents with learning difficulties in the child protection system: experiences and perspectives. *Journal of Intellectual Disabilities* 9: 109–129.
- Booth T and Booth W (2006) The uncelebrated parent: stories of mothers with learning difficulties caught in the child protection net. *British Journal of Learning Disabilities* 34: 94–102.
- Calderon R and Greenberg MT (2010) Challenges to parents and professionals in promoting socioemotional development in deaf children. In: Spencer PE, Erting C and Marschark M. (eds) *The Deaf Child in the Family and at School*. Didcot: Taylor & Francis e-Library, pp. 167–186.
- Collings S and Llewellyn G (2012) Children of parents with intellectual disability: facing poor outcomes or faring okay? *Journal of Intellectual & Developmental Disability* 37: 65–82.
- Conder J, Mirfin-Veitch B and Sanders J (2008) 'I've got to think of him . . .': relationships between parents with an intellectual disability and foster parents. *Developing Practice* 21: 17–25.

- Darbyshire LV and Stenfort Kroese B (2012) Psychological well-being and social support for parents with intellectual disabilities: risk factors and interventions. *Journal of Policy and Practice in Intellectual Disabilities* 9: 40–52.
- Embregts PJCM (2011) *Zien, bewogen worden, in beweging komen [See, be moved, start moving]*. Tilburg, The Netherlands: Tilburg University.
- Feldman MA (1994) Parenting education for parents with intellectual disabilities: a review of outcome studies. *Research in Developmental Disabilities* 15: 299–332.
- Forrester-Jones R, Carpenter J, Coolen-Schrijner P, et al. (2006) The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities* 19, 285–295. DOI: 10.1111/j.1468-3148.2005.00263.x.
- Goodinge S (2000) *A Jigsaw of Services. Inspection of services to support disabled adults in their parenting roles*. UK: Department of Health.
- Gould S and Dodd K (2014) ‘Normal people can have a child but disability can’t’: the experiences of mothers with mild learning disabilities who have had their children removed. *British Journal of Learning Disabilities* 42: 27–37.
- Hastings RP and Remington B (1994) Rules of engagement: Toward an analysis of staff responses to challenging behavior. *Research in Developmental Disabilities*, 15, 279–298.
- Jones N (2013) Good enough parents? Exploring attitudes of family centre workers supporting and assessing parents with learning difficulties. *Practice* 25: 169–190.
- Kazak AE (1989) Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. *Journal of Consulting and Clinical Psychology* 57: 25–30.
- Liberati A, Altman DG, Tetzlaff J, et al. (2009) The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *The BMJ* 339: b2700.
- Llewellyn G (1995) Relationships and social support: views of parents with mental retardation/intellectual disability. *Mental Retardation* 33: 349–363.
- Llewellyn G (1997) Parents with intellectual disability learning to parent: the role of experience and informal learning. *International Journal of Disability, Development and Education* 44: 243–261.
- Llewellyn G and Hindmarsh G (2015) Parents with intellectual disability in a population context. *Current Developmental Disorders Reports* 2: 119–126.
- McConnell D, Llewellyn G and Bye R (1997) Providing services for parents with intellectual disability: parent needs and service constraints. *Journal of Intellectual & Developmental Disability* 22: 5–17.
- McGhee J and Hunter S (2011) The Scottish children’s hearings tribunals system: a better forum for parents with learning disabilities? *The Journal of Social Welfare & Family Law* 33: 255–266.
- MacIntyre G and Stewart A (2012) For the record: the lived experience of parents with a learning disability – a pilot study examining the Scottish perspective. *British Journal of Learning Disabilities* 40: 5–14.
- Mayes R and Llewellyn G (2012) Mothering differently: narratives of mothers with intellectual disability whose children have been compulsorily removed. *Journal of Intellectual & Developmental Disability* 37: 121–130.
- Mayes R, Llewellyn G and McConnell D (2008) Active negotiation: mothers with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disability* 21: 341–350.
- Meppelder M, Hodes M, Kef S, et al. (2014) Expecting change: mindset of staff supporting parents with mild intellectual disabilities. *Research in Developmental Disabilities* 35: 3260–3268.
- Pace R, Pluye P, Barlett G, et al. (2012) Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies* 49: 47–53.
- Pixa-Kettner U (1999) Follow-up study on parenting with intellectual disability in Germany. *Journal of Intellectual & Developmental Disability* 24: 75–93.
- Pluye P, Gagnon MP, Griffiths F, et al. (2009) A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *International Journal of Nursing Studies* 46: 529–546.

- Pluye P, Robert E, Cargo M, et al. (2011) *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Montreal: McGill University. Available at: <http://mixedmethodsappraisaltoolpublic.pbworks.com> (accessed 23 September 2018).
- Rawls J (1999) *A Theory of Justice* (revised ed). Cambridge: Harvard University Press.
- Schalock RL (2004) The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203–216. DOI: 10.1111/j.1365-2788.2003.00558.x.
- Schuengel C, Kef S, Hodes MW, et al. (2017) Parents with intellectual disability. *Current Opinion in Psychology* 15: 50–54.
- Starke M (2010) Encounters with professionals: views and experiences of mothers with intellectual disability. *Journal of Intellectual Disabilities* 14: 9–19.
- Starke M (2011) Supporting families with parents with intellectual disability: views and experiences of professionals in the field. *Journal of Policy and Practice in Intellectual Disabilities* 8: 163–171.
- Stenfert Kroese BS, Hussein H, Clifford C, et al. (2002) Social support networks and psychological well-being of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 15: 324–340.
- Strike R and McConnell D (2002) Look at me, listen to me, I have something important to say. *Sexuality and Disability* 20: 53–63.
- Tarleton B and Ward L (2007) ‘Parenting with support’: the views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 4: 194–202.
- Tarleton B, Ward L and Howarth J (2006) Finding the right support. A review of issues and positive practice in supporting parents with learning difficulties and their children. Available at: <https://baringfoundation.org.uk/wp-content/uploads/2014/10/Findingrightsupport.pdf> (accessed 23 September 2018).
- Thomas J and Harden A (2008) Methods for thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology* 8: 45.
- Thompson JR, Bradley V, Buntinx WHE, et al. (2009) Conceptualizing supports and the support needs of people with intellectual disabilities. *Intellectual and Developmental Disabilities* 47: 135–146.
- Traustadóttir R and Sigurjónsdóttir HB (2008) The ‘mother’ behind the mother: three generations of mothers with intellectual disabilities and their family support networks. *Journal of Applied Research in Intellectual Disabilities* 21: 331–340.
- United Nations. *Convention on the rights of persons with disabilities*. New York: United Nations, 2006.
- Ungar M (2009) Overprotective parenting: helping parents provide children the right amount of risk and responsibility. *The American Journal of Family Therapy* 37: 258–271.
- Van Asselt-Goverts AE, Embregts PJCM and Hendriks AHC (2013) Structural and functional characteristics of the social networks of people with mild intellectual disabilities. *Research in Developmental Disabilities*, 34, 1280–1288. DOI: 10.1016/j.ridd.2013.01.012.
- Van Asselt-Goverts AE, Embregts PJCM and Hendriks AHC (2015) Social networks of people with mild intellectual disabilities: characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research* 59: 450–461.
- Wade C, Llewellyn G and Matthews J (2011). Modeling contextual influences on parents with intellectual disability and their children. *American Journal on Intellectual and Developmental Disabilities* 6: 419–437.
- Wade CM, Mildon RL and Matthews JM (2007) Service delivery to parents with an intellectual disability: family-centred or professionally centred? *Journal of Applied Research in Intellectual Disabilities* 20: 87–98.
- Walsh D and Downe S (2005) Meta-synthesis method for qualitative research: a literature review. *Journal of Advanced Nursing* 50: 204–211.
- Wilson S, McKenzie K, Quayle E, et al. (2013) The postnatal support needs of mothers with an intellectual disability. *Midwifery* 29: 592–598.